DOCUMENT RESUME

ED 427 477 EC 307 048

TITLE	A Perspective on Changes in Health Care for Children and Youth with Special Health Needs. CYDLINE Reviews.
INSTITUTION	Minnesota Univ., Minneapolis. National Center for Youth with Disabilities.
SPONS AGENCY	Health Resources and Services Administration (DHHS/PHS), Washington, DC. Maternal and Child Health Bureau.
PUB DATE	1998-08-00
NOTE	39p.
CONTRACT	1MCJ27R002-02
AVAILABLE FROM	National Center for Youth with Disabilities, Institute for Health & Disability, University of Minnesota, Box 721, 420 Delaware St., SE, Minneapolis, MN 55455; Tel: 612-626-2825; Tel (V/TTY): 612-624-3939; e-mail: ncyd@gold.tc.umn.edu or instihd@tc.umn.edu
PUB TYPE	Reference Materials - Bibliographies (131)
EDRS PRICE	MF01/PC02 Plus Postage.
DESCRIPTORS	Annotated Bibliographies; Child Health; Children; *Chronic Illness; Federal Programs; *Health Insurance; *Health Maintenance Organizations; *Health Services; Incidence; Medical Education; *Mental Health Programs; Outcomes of Treatment; *Special Health Problems; Youth
IDENTIFIERS	*Medicaid

ABSTRACT

This collection of annotated bibliographies focuses on managed health care and children and youth with special health care needs. Resources are divided into bibliographic materials and educational materials which cover the following topics: (1) demographics and children with special health needs (3 resources); (2) managed health care services (12 resources); (3) Medicaid and managed health care (6 resources); (4) managed care and children with special health needs (27 resources); (5) quality assurance and performance measurement (19 resources); (6) managed care and public health (3 resources); (7) medical education and managed care (9 resources); (8) managed care and children with special health needs (20 resources); (9) mental health (4 resources); (10) Medicaid and managed care (4 resources); (11) family voices (5 resources); and (12) medical homes for children with special health care needs (3 resources). (CR)

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CYDLINE Reviews:

A Perspective on Changes in Health Care for Children and Youth with Special Health Needs

August 1998

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University of Minnesota
Division of General Pediatrics
and Adolescent Health

EC 307048

The National Center for Youth with Disabilities is located in the Institute for Health & Disability, Division of General Pediatrics and Adolescent Health, at the University of Minnesota. The Center is partially supported by a grant from the Maternal and Child Health Bureau, Division of Services for Children with Special Health Needs, Department of Health and Human Services. The Center's mission is to raise awareness of the needs of youth with disabilities; foster coordination and collaboration among agencies, professionals, parents, and youth in planning and providing services; and provide technical assistance and consultation.

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This publication is supported through grant 1MCJ27R002-02 from the Maternal and Child Health Bureau, Health Services Resource Administration.

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Welcome to this issue of *CYDLINE* Reviews, a publication of "Project Connect," a managed care project funded by the Maternal and Child Health Bureau, Health Services Resource Administration. This issue is the second to focus on managed health care and children and youth with special health care needs.

Managed care has become the dominant health care delivery system in the United States. Will it meet the needs of children, adolescents and adults with chronic or disabling conditions? Even though questions remain to be answered, increasing numbers or persons with chronic illnesses and disabilities, including children and adolescents, are being enrolled in managed care organizations. Attention is quite naturally turning to evaluation of the quality of their health care, measures of patient and parent satisfaction with care and health outcomes. Health care providers, parents, and disability advocates are all participating in the health care debate.

The definition of children with chronic health conditions is an important issue that has recently been addressed by the Maternal and Child Health Bureau. Managed care organizations cannot provide appropriate quality care to these children and adolescents if they can't identify them. Also, managed care organizations must have quality assurance and patient satisfaction measures that are appropriate for children and adolescents with chronic illnesses or disabilities. Health care systems are experimenting with new and innovative models of care in order to reduce unnecessary goal is to meet the diverse health and psychosocial needs of children and adolescents with chronic or disabling conditions and to enable these children and their families to have the best possible quality of life.

There are many questions, but, as yet, relatively few answers. There is little in the literature that reflects the outcome data necessary to determine if the needs of people with special health care needs will, in fact, be met by managed care organizations. This publication will provide an overview of many of the issues for children and adolescents as well as abstracts of resources for those who have use for information about health care reform issues and managed care. We have also included references that provide basic demographic data in response to the number of requests for that information.

For those new to these Reviews, this collection of annotated bibliographies is drawn from NCYD's National Resource Library. The National Resource Library is a computerized, comprehensive database containing information about youth with chronic illnesses and disabilities, and it includes up-to-date expertise, programs, and literature of all relevant disciplines.

Nearly 200 journals are regularly reviewed as are relevant books and non-published materials. New entries are added to the library on a regular basis. Topics in the Bibliographic File include chronic illness or disabling conditions; psychosocial issues; social issues; developmental processes; family; sexuality; education; employment and vocational rehabilitation; community and independent living; service approaches; professional issues; and policy, planning, legal rights, issues, and health issues.

In addition to the Bibliographic File, the National Resource Library also includes a Health Care Reform File and an Educational Materials File with information on resources for professional development and programming usage.

The National Resource Library contains abstracts of current information on children and youth with special health needs and is housed on the world wide web: http://www.cyfc.umn.edu/NRL/. For information, contact an NCYD Information Specialist.

Issues of *CYDLINE* Reviews that may be ordered are:

- ***Transition from Pediatric to Adult Health Care for Youth with Disabilities and Chronic Illnesses***
- ***Adolescents with Chronic Illnesses—Issues for School Personnel***
- ***Promoting Decision-Making Skills by Youth with Disabilities—Health, Education, and Vocational Choices***
- ***An Introduction to Youth with Disabilities (In English or Spanish)***
- ***Substance Use by Youth with Disabilities and Chronic Illnesses***
- ***An Introductory Guide for Youth and Parents (In English or Spanish)***
- ***Issues in Sexuality for Adolescents with Chronic Illnesses and Disabilities***
- ***Vulnerability and Resiliency: Focus on Children, Youth, and Families***
- ***Youth with Disabilities and Chronic Illnesses: International Issues***
- ***Race and Ethnicity: Issues for Adolescents with Chronic Illnesses and Disabilities***
- ***Recreation and Leisure: Issues for Adolescents with Chronic Illnesses and Disabilities***
- ***Sports and Athletics: Issues for Adolescents with Chronic Illnesses and Disabilities***
- ***Issues in Nutrition for Adolescents with Chronic Illnesses and Disabilities***
- ***Developing Social Skills: Issues for Adolescents with Chronic Illnesses and Disabilities***
- ***Children and Youth with Disabilities in a Changing Health Care Environment***
- ***A Perspective on Changes in Health Care for Children and Youth with Special Health Needs***

NCYD has other publications available, including newsletters, special reports on issues unique to adolescents and youg adults with chronic or disabling conditions, and ***F.Y.I. Bulletin*** (fact Sheets presenting statistical and demographic data illustrated with tables, charts, and graphs). If you wish to receive a Publications List or would like information about the National Resource Library, our Center can be reached at **612/626-2825, 612/624-3939 (V/TTY), Fax: 612/626-2134, or use our e-mail address: ncyd@gold.tc.umn.edu.**

We invite you to visit our Web site: http://www.peds.umn.edu/Centers/ihd.

Thank you for your interest in NCYD. We hope you will take the time to read through this issue of NCYD's *CYDLINE* Reviews and share the contents with others.

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BIBLIOGRAPHIC MATERIALS

Demographics and Children with Special Health Needs

AUTHOR: Newacheck PW; Halfon N.
TITLE: **Prevalence and impact of disabling chronic conditions in childhood.**
SOURCE: *American Journal of Public Health* 1998 Apr; 88(4):610-17.

ABSTRACT: The authors use data from the 1992-94 National Health Interview Survey to provide a national profile of the prevalence and impact of chronic conditions causing childhood disability. The effects of disability on the education and health care systems are also assessed.

AUTHOR: Newacheck PW; Hughes DC; Stoddard JJ.
TITLE: **Children's access to primary care: Differences by race, income, and insurance status.**
SOURCE: *Pediatrics* 1996 Jan; 97(1):26-32.

ABSTRACT: The authors evaluated data from the 1987 National Medicare Expenditure Survey to determine access to use of primary care services for children who are poor, minority, and/or uninsured. Data indicate that poor, minority, and/or uninsured children, either in one risk or multiple risk groups, fare worse than those children who are not at risk. The authors call for comprehensive reform strategies rather than simple insurance reforms.

AUTHOR: Newacheck PW; Strickland B; Shonkoff JP; et al.
TITLE: **An epidemiologic profile of children with special health care needs.**
SOURCE: *Pediatrics* 1998 Jul; 102(1):117-23.

ABSTRACT: The Maternal and Child Health Bureau has developed a new definition of children with special health care needs (CSHCN). The authors examined the 1994 National Health Interview Survey on disability to operationalize the new definition. The survey found that 18% of U.S. children have special health needs, and a disproportionate number are poor and socially disadvantaged.

Managed Health Care Services

AUTHOR: Ad Hoc Task Force on Definition of the Medical Home.
TITLE: **The medical home.**
SOURCE: *Pediatrics* 1992 Nov; 90(5):774.

ABSTRACT: This policy statement advocates for the provision of a medical home for infants, children, and adolescents. Health care services should include preventive care; ambulatory care and inpatient care for acute illness; continuity of care; subspecialty care and referrals; interaction with school and community agencies; and maintenance of medical information in central records and databases.

AUTHOR Bergthold LA.
TITLE **Medical necessity: Do we need it?**
SOURCE *Health Affairs* 1995; 14(4):180-9.

ABSTRACT This article reviews the history of the term "medical necessity" and suggests ways the use of the term by insurance providers must change with health care reform. The author outlines the debate surrounding this terminology and stresses the need for additional investigation of the implications for the general public.

AUTHOR Brindis C.
TITLE **Promising approaches for adolescent reproductive health service delivery. The role of school-based health centers in a managed care environment.**
SOURCE *Western Journal of Medicine* 1995 Sep; 163(3 Suppl):50-6.

ABSTRACT The author discusses current and future relationships between school-based health care centers and managed health care. Managed care can well serve adolescents because of its focus on early intervention and preventive health care. The author advocates for managed care organizations to appreciate the benefits of investing in the health of adolescents even though the benefits may not be realized until sometime in the future. The author outlines the health care needs of adolescents, the value of providing services in school-based clinics, and both the benefits and possible problems of managed health care.

AUTHOR Budetti P; Feinson C.
TITLE **Ensuring adequate health care benefits for children and adolescents.**
SOURCE *The Future of Children* 1993 Sum/Fall; 3(2):37-59.

ABSTRACT This theme issue on health care reform includes an article which addresses ensuring adequate health care benefits for children and adolescents. Benefits that should be included in a health reform package are described: traditional medical services, preventive services, chronic care services, and orphan services. An outline of the comprehensive services recommended for women, infants, children and adolescents is included in the appendix.

AUTHOR Ellwood PM; Lundberg GD.
TITLE **Managed care: A work in progress.**
SOURCE *JAMA* 1996 Oct; 2(13):1083-6.

ABSTRACT The authors believe that doctors should be active in determining the future of America's health care systems. The history of HMOs and their evolution to the present day is reviewed. The authors advocate for national standards, quality measurement, risk adjustment, and reliance on patients' opinions of care.

AUTHOR English A; Kapphahn C; Perkins J; et al.
TITLE **Meeting the health care needs of adolescents in managed care: A position paper of the Society for Adolescent Medicine.**
SOURCE *Journal of Adolescent Health* 1998; 22(4):271-7.

ABSTRACT This position statement from the Society for Adolescent Medicine identifies four key goals for the treatment of adolescents under managed care, including: access to comprehensive, coordinated care; age-appropriate, adolescent-focused services; adequate financial coverage for services; and adolescent-specific quality control standards.

AUTHOR English A; Kapphahn C; Perkins J; et al.
TITLE **Meeting the health care needs of adolescents in managed care: A background paper.**
SOURCE *Journal of Adolescent Health* 1998; 22(4):278-92.

ABSTRACT The authors describe the recent growth of managed care and analyze its implications for adolescents and their unique health care needs. Potential benefits and potential problems for adolescents in managed care are described, and the authors provide guidelines to ensure that the special health care needs of adolescents are met in managed care arrangements.

AUTHOR Ginzberg E; Ostow M.
TITLE **Managed care—A look back and a look ahead.**
SOURCE *New England Journal of Medicine* 1997 Apr; 336(14):1013-4, 1018-20.

ABSTRACT The authors discuss the importance of the history of managed care and suggest the course that managed care will take in the next few years.

AUTHOR Kohrman AF.
TITLE **Financial access to care does not guarantee better care for children.**
SOURCE *Pediatrics* 1994 Mar; 93(3):506-8.

ABSTRACT The author cautions that without careful planning, health care reform plans driven by financial concerns and cost-containment will not guarantee better care for children and adolescents, particularly those with chronic illnesses or disabilities. To improve the quality of services to children with special health care needs, changes in service delivery coordination are recommended.

AUTHOR Lapensee KT.
TITLE **Pricing specialty carve-outs and disease management programs under managed care.**
SOURCE *Managed Care Quarterly* 1997; 5(2):10-9.

ABSTRACT The author describes traditional case management programs and contrasts them with newer disease management programs which emphasize proactive clinical interventions and patient education.

AUTHOR Sandy LG; Gibson R.
TITLE **Managed care and chronic care: Challenges and opportunities.**
SOURCE *Managed Care Quarterly* 1996 Spr; 4(2):5-11.

ABSTRACT The authors believe that managed care organizations are better organized to treat acute rather than chronic conditions. They call for increased integration of care, including primary care, specialty care and non-medical services, with emphasis on quality of life rather than cure. The authors give recommendations for HMOs as they redesign care for patients with chronic illnesses.

AUTHOR Wehr E; Jameson EJ.
TITLE **Beyond benefits: The importance of a pediatric standard in private insurance contracts to ensuring health care access to children.**
SOURCE *The Future of Children* 1994 Win; 4(3):115-33.

ABSTRACT An examination of restrictions on children's access to health care based on exclusions in indemnity insurance and managed care plan policies. The following issues are addressed: the need for a pediatric standard, private health insurance regulation, the special needs of children, administrative barriers to care, contractual barriers to care, and reform proposals and pediatric standard.

Medicaid and Managed Health Care

AUTHOR American Academy of Pediatrics Committee on Health Financing
TITLE **American Academy of Pediatrics Committee on Child Health Policy: Medicaid policy statement.**
SOURCE *Pediatrics* 1994 Jan; 93(1):135-6.

ABSTRACT This policy statement outlines recommendations for the improvement of the Medicaid program. The Academy of Pediatrics proposes the development of a new program, "Children First," which would replace Medicaid with a private, universal insurance system.

AUTHOR Epstein R.
TITLE **Finding your way through the Medicaid maze.**
SOURCE *Exceptional Parent* 1994 Sep; 24(10):26-8.

ABSTRACT This article offers general information about the often complex and confusing Medicaid system. The author lists resources parents can utilize if claims are denied.

AUTHOR Gadomski A; Jenkins P; Nichols M.
TITLE **Impact of a Medicaid primary care provider and preventive care on pediatric hospitalization.**
SOURCE *Pediatrics* 1998; 101(3):460(e1).

ABSTRACT This study was conducted to determine whether a Medicaid managed care program could effectively reduce unnecessary hospitalizations. Results indicated that such a program could reduce unnecessary hospitalizations through increased access to care and higher numbers of preventive visits. This abstract can be found on the Pediatrics electronic pages section. The complete original article is available on Pediatrics electronics pages on the world wide web: <http://pediatrics.org/cgi/content/full/101/3/el>.

AUTHOR Gold M; Sparer M; Chu K.
TITLE **Medicaid managed care: Lessons from five states.**
SOURCE *Health Affairs* 1996 Fall; 15(3):153-66.

ABSTRACT This article summarizes the Medicaid managed care initiative for five states. The report addresses: 1) Administrative issues such as enrollment and marketing, eligibility and oversight; 2) Delivery and coordination, including discussion of delivery systems and structures, capitation rates and risk adjustment, benefits and carve-outs, enabling services and Medicaid, cost-sharing, participation by commercial HMOs, and transitional issues; and 3) Health care system effects, including access to care, safety net providers and the uninsured. Conclusions and lessons are provided, including 10 lessons that can increase the potential for success. This report is also available from The Commonwealth Fund, New York, NY.

AUTHOR RosenbaumS.
TITLE **A look inside Medicaid managed care.**
SOURCE *Health Affairs* 1997 Jul; 16(4):266-71.

ABSTRACT The author reviewed contracts between Medicaid and managed care organizations. This report describes different purchasing strategies, the use of dual coverage and "safety-net" providers, as well as coverage of the elderly and persons with disabilities. Examples from various contracts are provided.

AUTHOR West DW; Stuart ME; Duggan AK; et al.
TITLE **Evidence for selective health maintenance organization enrollment among children and adolescents covered by Medicaid.**
SOURCE *Archives of Pediatric and Adolescent Medicine* 1996 May; 150:503-7.

ABSTRACT This study examined unintentional selection bias in Medicaid patients receiving care from health maintenance organizations (HMOs). The study found that children whose parents chose HMOs tended to have fewer chronic health conditions and less history of hospitalization. The financial implications of this unintended selection bias are discussed along with ways to correct the problem.

Managed Care and Children with Special Health Needs

AUTHOR Anderson B.
TITLE **Caring for children with special needs in HMOs: The consumer's perspective.**
SOURCE *Managed Care Quarterly* 1996 Sum; 4(3):36-40.

ABSTRACT The author believes that HMOs should design and include policies that meet the special needs of children with chronic illness. Plans should provide clear information to families about available services to help them choose an HMO. HMOs should have a staff member experienced in pediatric chronic illness who can respond to families' questions.

AUTHOR Andrews JS; Anderson GF; Han C; et al.
TITLE **Pediatric carve outs. The use of disease-specific conditions as risk adjusters in capitated payment systems.**
SOURCE *Archives of Pediatric and Adolescent Medicine* 1997 Mar; 151(3):236-42.

ABSTRACT The authors examined a list of disease-specific pediatric conditions to determine if they should be considered for separate reimbursement schedules. Ten percent of cases accounted for more than 50% of spending. These findings could be used by insurers to identify conditions needing capitated reimbursement.

AUTHOR Collis-Mele N.
TITLE **Medicaid managed care and Title V services for children with special health care needs.**
SOURCE *Abstract Book/Association for Health Services Research* 1997; 14:148.

ABSTRACT This study examined whether the health care needs of children with disabilities were being met by Medicaid managed care. Findings were subject to gatekeeping and pre-authorization requirements. Some plans relied on adult subspecialists to care for children and disrupted longstanding patient-provider relationships. This abstract book was distributed at the 1997 annual meeting of the Association for Health Services Research. The abstract can be found on the Association's web site: http://www.ahsr.org.

AUTHOR Committee on Children with Disabilities
TITLE **General principles in the care of children and adolescents with genetic disorders and other chronic health conditions.**
SOURCE *Pediatrics* 1997 Apr; 99(4):643-4.

ABSTRACT This policy statement from the American Academy of Pediatrics (AAP) describes issues for pediatricians to consider when caring for children and youth with genetic disorders or other chronic health conditions. To provide family-oriented community-based services, pediatricians must be aware of the following issues: the provision of a "medical home" for patients, coordination of care provided by a multidisciplinary team of service providers, the need for increased vigilance during periods of transition, knowledge of community-based public and private programs, and provision of preventive health care services.

AUTHOR Epstein R.
TITLE **Managing managed care.**
SOURCE *Exceptional Parent* 1997 June; 21(6):76.

ABSTRACT An overview of managed care for parents of children with disabilities.

AUTHOR Fowler EJ; Anderson GF.
TITLE **Capitation adjustments for pediatric populations.**
SOURCE *Pediatrics* 1996 Jul; 98(1):10-17.

ABSTRACT This study compared models of claims-based capitation adjustment for pediatric populations. All models had gaps of underpayment for high-risk children. Further research is needed to keep children with chronic conditions from being hurt by pediatric capitation adjustment methods.

AUTHOR Gay JC; Muldoon JH; Neff JM; et al.
TITLE **Profiling the health services needs of populations: Descriptions and uses of the NACHRI classification of congenital and chronic health conditions.**
SOURCE *Pediatric Annals* 1997 Nov; 26(11):655-63.

ABSTRACT This article describes a classification system developed by the National Association of Children's Hospital and Related Institutions (NACHRI). Classification systems are used to predict health care expenditures for various populations, including children with special health care needs.

AUTHOR Gray HB.
TITLE **Managed care for children with special health care needs: Michigan's approach.**
SOURCE *Pediatric Annals* 1997 Nov; 26(11):668-72.

ABSTRACT The author describes the process used in Michigan to develop a statewide managed care network for children with special health care needs (CSHCN). Central to the process was the establishment of guiding principles and values which to detemine outcomes. A Request for Proposals was issued by the state in 1996, and they have plans to develop a reasonable capitation rate. Most importantly, physicians, families, hospitals and other major stakeholders worked together to provide high quality cost effective care to CSHCN.

AUTHOR Gruskin AB.
TITLE **Children with special healthcare needs: Introduction.**
SOURCE *Pediatric Annals* 1997 Nov; 26(11):653-4.

ABSTRACT This article introduces a special issue of Pediatric Annals. The author defines terms and describes the various professionals who work with children with special health needs..

AUTHOR Ireys HT; Anderson GF; Shaffer TJ; et al.
TITLE **Expenditures for care of children with chronic illnesses enrolled in the Washington state Medicaid program, fiscal year 1993.**
SOURCE *Pediatrics* 1997 Aug; 100(2 Pt 1):197-204.

ABSTRACT This study calculated expenditures for children with selected chronic health conditions who were enrolled in the Washington State Medicaid program and compared them with payments for all Medicaid-enrolled children. Medical care for children with selected chronic health conditions was more expensive than for children in general, depending on the condition. A relatively few children accounted for the majority of expenditures. Data suggest that different conditions will need to be kept distinct for purposes of establishing payment rates. Further analyses are needed to identify risk-adjustment strategies to support delivery of high quality services to these children as they move into managed care environments.

AUTHOR Jessop DJ; Stein REK.
TITLE **Providing comprehensive health care to children with chronic illness.**
SOURCE *Pediatrics* 1994 Apr; 93(4):602-7.

ABSTRACT This study was designed to determine which of two modes of treatment would provide more comprehensive care for children with chronic illnesses. The Pediatric Home Care (PHC) outreach program was contrasted with standard care (SC). Findings indicated that the PHC program provided more comprehensive, coordinated care to children with chronic health conditions. Mothers of patients reported greater satisfaction and better access to health care services. The authors concluded that comprehensive care improved medical services and psychosocial supports for families of children with chronic illnesses.

AUTHOR Lambert EW; Guthrie PR.
TITLE **Clinical outcomes of a children's mental health managed care demonstration.**
SOURCE *Journal of Mental Health Administration* 1996 Win; 23(1):51-68.

ABSTRACT This study of mental health outcomes compared children and adolescents treated in a mental health managed care demonstration project to children and adolescents treated in traditional mental health services. Data were collected six months and one year after baseline data. Outcomes were evaluated in several ways: diagnostic change; parents' opinions about child improvement; key mental health measures; and direct reports of functioning. Although the average child showed improvement, neither site had superior results. Implications for policy are discussed.

AUTHOR Lozano P; Fishman P; VonKorff M.
TITLE **Health care utilization and cost among children with asthma who were in a health maintenance organization.**
SOURCE *Pediatrics* 1997 Jun; 99(6):757-64.

ABSTRACT The authors discuss health services used by children with asthma in a health maintenance organization. These children used more health services than other children, although the majority of health care costs came from non-asthma services.

AUTHOR McManus MA; Fox HB.
TITLE **Enhancing prevention and primary care for children with chronic or disabling conditions served in health maintenance organizations.**
SOURCE *Managed Care Quarterly* 1996; 4(3):19-29.

ABSTRACT The authors describe seven design elements for improving preventive and primary care for children with chronic conditions. These recommendations are illustrated with examples from HMOs and state Medicaid programs. The authors describe how these seven elements will become more important as increasing numbers of children with chronic conditions receive their health care from managed care organizations.

AUTHOR McPherson M; Arango P; Fox H; et al.
TITLE **A new definition of children with special health care needs.**
SOURCE *Pediatrics* 1998 Jul; 102(1):137-40.

ABSTRACT The authors outline a new definition of children with special health care needs and the process used to develop it. Changes in public and private health care services made a new definition necessary. The new definition includes children who require increased health and related services as well as children at increased risk of developing a chronic physical, developmental, behavioral or emotional condition.

AUTHOR Narkewick RM; Duncan P; Hassler C; et al.
TITLE **Pediatricians partnering with states to assure that children with special health care needs are provided appropriate services: The Vermont experience with managed Medicaid.**
SOURCE *Pediatric Annals* 1997 Nov; 26(11):664-7.

ABSTRACT This article describes Vermont's effort to build a managed care system for children with special health care needs (CSHCN). The effort was multidisciplinary with input from policymakers, physicians, and the state health department. The authors give some specific details from Vermont's plan as well as examples and general principles for providing managed care to CSHCN and their families.

AUTHOR Neff JM; Anderson G.
TITLE **Protecting children with chronic illness in a competitive marketplace.**
SOURCE *JAMA* 1995 Dec; 274(23):1866-9.

ABSTRACT Studies indicate that health care costs for children with chronic illnesses are five times greater than those of healthy children. Children with chronic conditions are particularly vulnerable in today's competitive health care environment. It is necessary to explore viable options that ensure the availability of comprehensive health care at reasonable costs. The authors advocate for the development of a capitation system that reflects the higher costs of health care for children with chronic health conditions.

AUTHOR Newacheck PW; Stein RE; Walker DK; et al.
TITLE **Monitoring and evaluating managed care for children with chronic illness and disabilities.**
SOURCE *Pediatrics* 1996 Nov; 98(5):952-8.

ABSTRACT The authors address the critical need for scientific assessment of managed health care for children and youth with chronic conditions. Information could result in adjustments, modifications and improved outcomes. The authors propose two research strategies and identify seven key domains that should be assessed.

AUTHOR Perrin JM; Kuhlthau K; Klein Walker D; et al.
TITLE **Monitoring health care for children with chronic conditions in a managed care environment.**
SOURCE *Maternal and Child Health Journal* 1997; 1(1):15-23.

ABSTRACT The authors reviewed the research and policy literature related to managed care and the special needs of families with children with chronic conditions. They also reviewed current and proposed plans of federal, state, and private groups for monitoring care provided by managed care plans to children with chronic conditions. Assessment of their care will be difficult because of the relative rarity of many childhood conditions and complex interactions among child, family and community. Child and family characteristics are described, and essential features of monitoring systems are outlined. The authors conclude that monitoring managed care for children with chronic conditions will require public health agencies and health care providers to systematically define populations, assess across a variety of conditions, and monitor several essential domains.

AUTHOR Rappo PD.
TITLE **Get health plans to play by your rules.**
SOURCE *Medical Economics* 1997 Jan 13; 74(1):125-6.

ABSTRACT The author explains how he manages the care of his pediatric patients with chronic health conditions so as to ensure adequate reimbursement for their care from managed health care plans. Because it is difficult to assess and adjust risk relative to chronic conditions, the physician, the family and the health plan must communicate and determine policies and procedures that are fair to all.

AUTHOR Rappo PD.
TITLE **The care of children with chronic illness in primary care practice: Implications for the pediatric generalist.**
SOURCE *Pediatric Annals* 1997 Nov; 26(11):687-95.

ABSTRACT The author addresses reasons pediatric generalists may be reluctant to provide primary care to children with chronic conditions. Concerns include not having sufficient time or knowledge, fears about insufficient medical reimbursement and increased medicolegal liability. The author offers advice for overcoming these barriers and practical tips for coordinating special health care.

AUTHOR Reid RJ; Hurtado MP; Starfield B.
TITLE **Managed care, primary care, and quality for children.**
SOURCE *Current Opinion in Pediatrics* 1996 Apr; 8(2):164-70.

ABSTRACT The authors review the benefits and negative aspects of various forms of managed care. They suggest that prepaid group practices improve primary care for children, however, access to specialty services is often limited. Better studies are necessary to examine the link between managed care and quality of care.

AUTHOR Rosenfeld LR.
BOOK ***Your child and health care: A "dollars & sense" guide for families with special needs.***
SOURCE Paul H. Brooks: Baltimore, MD, 1994, 352.

ABSTRACT This book gives parents of children with chronic illnesses or disabilities information that will help them manage medical expenses and secure quality health care services for their children. The author provides answers to questions ranging from sources of financial help to reduction of expenses.

AUTHOR Smyth M; Haas D; Friebe M.
TITLE **The ups and downs for children with chronic illness.**
SOURCE *Managed Care Quarterly* 1995 Aut; 3(4):91-5.

ABSTRACT This study examined health care for children with chronic illness under health maintenance organizations. The paper describes a Medicaid Physicians Sponsor plan in Michigan which was set up to improve primary care for children with chronic illnesses. The authors identify advantages and barriers to providing primary care in a managed care system.

AUTHOR Stein RE; Bauman LJ; Westbrook LE; et a.
TITLE **Framework for identifying children who have chronic conditions: The case for a new definition.**
SOURCE *Journal of Pediatrics* 1993 Mar; 122(3):342-7.

ABSTRACT The authors review the traditional diagnostic list technique for identifying children with special health needs and suggest a non-categorical approach as an alternative. Components of the new framework are described.

AUTHOR Stein REK; Westbrook LE; Bauman LJ.
TITLE **The questionnaire for identifying children with chronic conditions: A measure based on a noncategorical approach.**
SOURCE *Pediatrics* 1997 Apr; 99(4):513-21.

ABSTRACT The authors report on the Questionnaire for Identifying Children with Chronic Conditions (QuICCC), a new instrument to identify children and adolescents with chronic health conditions which is based on a noncategorical framework. It uses the consequences of conditions as a method for identifying children with chronic health conditions independent of diagnosis. The QuICCC was found to be a practical instrument that successfully identified children with a wide range of chronic conditions and excluded those with acute illnesses or with conditions but no current consequences. It can be used for epidemiological purposes and has many potential applications in health care delivery research.

AUTHOR Weber KS.
TITLE **Phoenix Pediatrics: Practice management at its best.**
SOURCE *Exceptional Parent* 1998 Feb; 28(2):32-6.

ABSTRACT This article describes how a group of physicians in Phoenix, Arizona, deliver quality care while also dealing with the rules of managed care. In addition to describing how these physicians care for their patients, the author describes the clinic's advanced computer program that assists parents and physicians.

Quality Assurance and Performance Measurement

AUTHOR Angell M; Kassirer JP.
TITLE **Quality and the medical marketplace—following elephants.**
SOURCE *New England Journal of Medicine* 1996 Sep 12; 335(12):883-5.

ABSTRACT This editorial introduces a six-part series that addresses concerns about quality of care within managed care plans. Quality is a difficult quantity to assess, especially when health plans emphasize health of the whole population of enrollees, process rather than outcome as a quality measure, and preventive care rather than the management of complex illness. Health care plans can maximize patient satisfaction and quality scores by enrolling healthier patients rather than those with complex illnesses. It is essential to measure, monitor and make public the quality of competing health plans in order to protect patients and their doctors.

AUTHOR Bergman DA.
TITLE **Thriving in the 21st century: Outcome assessment, practice parameters, and accountability.**
SOURCE *Pediatrics* 1995 Oct; 96(4):831-5.

ABSTRACT The author writes about changes in the health care system and related challenges for pediatricians. The physicians new "clinical tool kit" should include practice guidelines and outcome assessment instruments, tools to document effective interventions.

AUTHOR Berwick DM.
TITLE **Part 5: Payment by capitation and the quality of care.**
SOURCE *New England Journal of Medicine* 1996 Oct 17; 335(16):1227-31.

ABSTRACT This article discusses the relationship between capitation and quality of care.. The author suggests principles that should increase the probability that capitation will reduce costs without jeopardizing the well-being of patients.

AUTHOR Blumenthal D.
TITLE **Part I: Quality of care—What is it?**
SOURCE *New England Journal of Medicine* 1996 Sep 19; 335(12):891-3.

ABSTRACT This article reviews definitions of quality of care and is the first in a series of articles addressing quality of care. The author discusses the growing importance of consumer preferences and values, the perspectives of health care plans and organizations, and the perspectives of purchasers of health care services (employers, unions, and consumer cooperatives). The debate over definition, measurement and quality must include health care professionals.

AUTHOR Blumenthal D.
TITLE **Part 4: The origins of the quality of care debate.**
SOURCE *New England Journal of Medicine* 1996 Oct 10; 335(15):1146-9.

ABSTRACT The author examines factors that have made quality of care a focus of the current health care debate, including: 1) A focus on reducing the cost of services without study to determine the effects of various approaches to quality, especially quality of care received by special populations or cost reduction techniques that compromise patient welfare; 2) Increased knowledge of ways to measure quality of care, including the use of clinical epidemiology, the growth of outcomes research, the growth of information systes, computer technology and communication techniques, and the use of quality management techniques; and 3) Changes in the criteia for optimal care which necessitate collaboration between health professionals and health care institutions.

AUTHOR Blumenthal D; Epstein AM.
TITLE **Part 6: The role of physicians in the future of quality management.**
SOURCE *New England Journal of Medicine* 1996 Oct 24; 335(17):1328-31.

ABSTRACT This article completes a 6-part series of articles that address quality assurance in medical care. The use of quality report cards is extensive in health care today, both to facilitate choices among health care plans and as a way of managing internal operations. Physicians should be hopeful because the development of new and more reliable quality measures and quality management can bring about improved capabilities in medical care.

AUTHOR Brook RH; Kamberg CJ; McGlynn EA.
TITLE **Health system reform and quality.**
SOURCE *JAMA* 1996 Aug 14; 276(6):476-80.

ABSTRACT The authors discuss current health system reform and the need for clinically-based quality control measures. Eight key issues related to cost and quality are identified. The authors also predict future challenges to health care reform, including potential friction between the goal of providing the best care to individual patients and the goal of maximizing the health of communities.

AUTHOR Brook RH; McGlynn EA; Cleary PD.
TITLE **Part 2: Measuring quality of care.**
SOURCE *New England Journal of Medicine* 1996 Sep 26; 335(12):966.

ABSTRACT The authors review various methods used to evaluate quality of care. Structural process and/or outcome data can be used; process and outcome data can be evaluated with implicit and explicit methods. Analysis of quality of care requires the development of criteria (practice guidelines), identification of data sources to evaluate compliance, and decisions about whether to measure process and/or outcome data. Assessment may vary depending on the method used, and quality of care cannot necessarily be generalized from one set of symptoms, diseases or medical functions to another.

AUTHOR Chassin MR.
TITLE **Part 3: Improving the quality of care.**
SOURCE *New England Journal of Medicine* 1996 Oct 3; 335(14):1060-3.

ABSTRACT This article addresses quality of care from the physician's viewpoint. Past efforts failed to measure quality outcomes for patients. New measurement tools allow physicians and hospitals to compare performance and make better informed clinical decisions. The author states that by focusing on quality improvement, physicians can improve patient outcomes and also regain more autonomy over the practice of medicine. Physicians can increase the focus on quality of care by working to reduce costs.

AUTHOR Enthoven AC; Vorhaus CB.
TITLE **A version of quality in health care delivery.**
SOURCE *Health Affairs* 1997 May/June; 16(3):44-57.

ABSTRACT The authors identify features they consider to be the most important for a quality health care system. They believe medical education should include managed care and quality measurement issues, and the government's role should be limited. Capitation and other financial issues are also discussed.

AUTHOR Forrest CB; Simpson L; Clancy C.
TITLE **Child health services research: Challenges and opportunities.**
SOURCE *JAMA* 1997 Jun 11; 277(22):1787-93.

ABSTRACT Quality assesment tools have been developed for adults under managed care, but appropriate quality assesment tools for children have yet to be developed. The authors argue for the importance of a separate focus on children and call for increased support for child health services research (CHSR). They suggest ways to strengthen CHSR.

AUTHOR Hibbard JH; Jewett JJ.
TITLE **Will quality report cards help consumers?**
SOURCE *Health Affairs* 1997 May; 16(3):218-28.

ABSTRACT The article discusses the use of quality report cards to evaluate health care. The study revealed that consumers often do not understand quality information. Further analysis is needed to determine what should be included in quality report cards.

AUTHOR Ireys HT; Grason HA; Guyer B.
TITLE **Assuring quality of care for children with special needs in managed care organizations: Roles for pediatricians.**
SOURCE *Pediatrics* 1996 Aug; 98(2):178-85.

ABSTRACT Increasing numbers of children with special health care needs (CSHCN) are being enrolled in managed care programs, however, few frameworks have been designed to assess the quality of care provided to CSHCN by managed care programs. The authors adopt the Institute of Medicine's definition of quality and identify six key components for assessment: content of service delivery systems, the nature of desired health outcomes, risks associated with service delivery, constraints of care, interpersonal dimensions, and attention to developmental issues. These components can be assessed at three levels: the individual, the health plan, and the community. Pediatricians and other child health professionals have critical roles to play in assuring that policies and practices within managed care organizations promote a high quality of care for this vulnerable population of children.

AUTHOR Lawrence DM.
TITLE **Quality lessons for public policy: A health plan's view.**
SOURCE *Health Affairs* 1997 May/June; 16(3):72-6.

ABSTRACT The author is chief executive officer of a large health plan. He describes lessons he's learned about improving quality in health care. These lessons include observations on care conditions, public policy, preserving the "culture of medicine," and funding research. He calls for strong, clearly defined public policy to support quality initiatives.

AUTHOR Mateo MA; Matzke K; Newton C.
TITLE **Designing measurements to assess care management outcomes.**
SOURCE *Nursing Care Management* 1998 Jan/Feb; 3(1):2-6.

ABSTRACT This article examines ways to measure case management outcomes. The authors outline goals of case management, tools used by case managers, identification of relevant measures, outcomes to be measured, and establishment of a data collection system.

AUTHOR McCormick MC.
TITLE **Quality of care: An overdue agenda.**
SOURCE *Pediatrics* 1997 Feb; 99(2):249-50.

ABSTRACT This commentary addresses the assessment and assurance of quality of care for pediatric populations. The author discusses the disadvantages of several assessment methods and offers more satisfactory components, including: better characterization of the patient population, severity measures, better characterization of the provision of care, development of a broader array of outcomes and changes in physician education.

AUTHOR McGlynn EA.
TITLE **Choosing chronic disease measures for HEDIS: Conceptual framework and review of seven clinical areas.**
SOURCE *Managed Care Quarterly* 1996 Sum; 4(3):54-77.

ABSTRACT The Health Plan Employer Data and Information Set (HEDIS) will be expanded in order to measure and analyze quality of health care for a greater number of chronic conditions. This article provides criteria for selecting which chronic conditions should be included and gives guidance as to which areas and outcomes should be measured.

AUTHOR McGlynn EA.
TITLE **Six challenges in measuring the quality of health care.**
SOURCE *Health Affairs* 1997 May/June; 6(3):7-25.

ABSTRACT The author explains quality monitoring and describes six challenges to developing quality measurements, including: Balancing the perspectives of patient, doctors and payers, and minimizing conflict between cost containment and quality goals. The author proposes ways government and the private sector might collaborate to develop appropriate quality monitoring systems.

AUTHOR Merritt TA; Palmer D; Bergman DA; et al.
TITLE **Clinical practice guidelines in pediatric and newborn medicine: Implications for their use in practice.**
SOURCE *Pediatrics* 1997 Jan; 99(1):100-14.

ABSTRACT The authors discuss the effects of clinical practice guidelines on the practice of pediatric and newborn medicine. Clinical practice guidelines have the potential to reduce health care costs and improve quality of care. The authors, however, believe that clinical practice guidelines have failed to live up to expectations. Further analysis is needed.

Managed Care and Public Health

AUTHOR Freeman P; Robbins A.
TITLE **National health care reform minus public health: A formula for failure.**
SOURCE *Journal of Public Health Policy* 1994 Fall; 15(3):261-82.

ABSTRACT The authors critique health care reform and provide a historical context as well as a prescription for the future. Topics addressed include: universal sickness insurance posing as comprehensive health care reform; beyond insurance, incorporating better health into reform; public health authority, a neglected foundation for reform; immunization; and the United Kingdom experience. Also available as part of the Occasional Paper Series from the John W. McCormack Institute of Public Affairs. Call 617/287-5550 for information.

AUTHOR Smith JL.
TITLE **Can managed care do it all?**
SOURCE *Health Systems Review* 1994 Nov/Dec; 27(6):34-37.

ABSTRACT The author addresses concerns about the ability of managed care systems to handle complicated public health problems. Tuberculosis is used as an example.

AUTHOR Altemeier III WA.
TITLE **Will managed care replace public health?**
SOURCE *Pediatric Annals* 1995 Dec; 24(12):620, 623.

ABSTRACT This article compares the functions of current public health services and managed care systems. The author warns that, although the two overlap in many areas, managed care cannot fully replace public health. This conclusion is based on the needs of uninsured patients and the key functions of public health clinics.

Medical Education and Managed Health Care

AUTHOR Badgett JT.
TITLE **General pediatric teaching clinics and managed care.**
SOURCE *Pediatrics* 1998 Apr; 101(4 Pt 2):775-778.

ABSTRACT Academic general pediatric divisions are responsible for training physicians for practice in managed care environments. The author discusses positive and negative implications of managed care in academic settings.

AUTHOR Behrman RE.
TITLE **Some unchanging values of pediatric education during a time of changing technology and practice.**
SOURCE *Pediatrics* 1996 Dec; 98(6 Pt 2):1249-54.

ABSTRACT This article outlines some of the challenges of educating pediatric residents for practice in managed care organizations. The author suggests methods of adapting older educational models to fit modern demands, and he points out things that cannot change if patients' needs are to be met.

AUTHOR Devries JM; Berkelhamer JE; Molteni RA; et al.
TITLE **Developing models for pediatric residency training in managed care settings.**
SOURCE *Pediatrics* 1998 Apr; 101(4 Pt 2):753-9.

ABSTRACT New educational objectives and curricula are necessary to train pediatric residents for practice in managed care environments. The authors discuss new knowledge and skills that will be required for proficiency, and they advocate for cooperation among physicians, educators, and managed care organizations.

AUTHOR Finkelstein JA..
TITLE **Pediatric residency training in an era of managed care: An introduction to proceedings of a national conference.**
SOURCE *Pediatrics* 1998 Apr; 101(4 Pt 2):735-8.

ABSTRACT The author provides an overview of critical issues addressed in a 1996 conference that focused on pediatric residency training in managed care settings. This article introduces a special supplement to the journal.

AUTHOR Fischel JE; Inkeles SL.
TITLE **Managed care and medical education: Can these two entities interact?**
SOURCE *Pediatrics* 1995 Jul; 96(1):171.

ABSTRACT The authors address the conflict between managed care and medical education. They stress the difficulty of satisfying both the educational and health care delivery goals of a modern health care system and offer some insights The author offers some insight into solving the problem.

AUTHOR | Frazier S; Hyman D; Altschuler S.
TITLE | **The changing health care environment: Implications for residency training.**
SOURCE | *Pediatrics* 1998 Apr; 101(4 Pt 2):795-803.

ABSTRACT | The shift to managed care is bringing with it changes in pediatric training and practice. The authors discuss how changes in training will strengthen graduate medical education and better prepare physicians for new health care delivery systems. The Philadelphia market is used for illustration.

AUTHOR | Norlin C; Osborn LM.
TITLE | **Organizational responses to managed care: Issues for academic health centers and implications for pediatric programs.**
SOURCE | *Pediatrics* 1998 Apr; 101(4 Pt 2):805-11.

ABSTRACT | Managed care's reimbursement system poses challenges to Academic Health Centers (AHC) and their pediatric programs. These challenges include competition for limited dollars and administrative and governance structures that are slow to change. The authors discuss these issues and describe the adaptations being made by four ACHs.

AUTHOR | Pan RJD; Finkelstein JA.
TITLE | **Pediatric education and managed care: A literature review.**
SOURCE | *Pediatrics* 1998 Apr; 101(4 Pt 2):739-745.

ABSTRACT | The authors conducted a literature review to study important issues for pediatric education in managed care environments. Curricular, administrative and financial questions need to be answered, including: what should be taught, who should be teaching it, where should it be taught, and how should it be paid for. More research and information are necessary.

AUTHOR | Williams RG; Stein LD; Leslei LK.
TITLE | **Training pediatricians for the evolving generalist-specialist interface in the managed care era.**
SOURCE | *Pediatrics* 1998 Apr; 101(4 Pt 2):779-83.

ABSTRACT | This article discusses necessary changes in pediatric training due to managed care. Because generalists will manage more of the care traditionally provided by subspecialists, pediatric resident training should include more exposure to both inpatient and oupatient subspecialty problems. The authors believe managed care also has negative effects on the necessary changes in pediatric training.

Managed Care and Children with Special Health Needs

TITLE	**The ABC's of Managed Care: Standards and Criteria for Children with Special Health Care Needs**
SUPPLIER	Institute for Family Centered Care
ADDRESS	7900 Wisconsin Ave., Ste. 405; Bethesda, MD 20814
PHONE	301/652-0281
PRODUCER	National Coalition for Family Leadership at the Egg Harbor Family Summit
ABSTRACT	This document provides a set of family-centered standards for managed care systems serving children with special health care needs (CSNCN) and their families. It was written by a group of parent leaders who met in Egg Harbor, Wisconsin, in 1995, and addresses principles of managed care for CSHCN, application of those principles to access, benefits, capacity, decision-making, evaluation and data, and financing. This report is designed to inform the delivery of heatlh care to CSHCN by managed health care organizations. It is also available on theInternet: <http://www.ichp.ufl.edu/MCH-NetLink>.

TITLE	**Analysis of the Implementation of the Pediatric Asthma Clinical Guideline**
YEAR	1997
SUPPLIER	Ann O'Fallon, Project ACCORD Coordinator,
ADDRESS	Minnesota Department of Health, MCSHN-Family Health Division, 717 Delaware St., PO Box 9441; Mnneapolis, MN 55440-9441
PHONE	612/623-5185
PRODUCER	Kaufer Flores S ; O'Fallon A.
ABSTRACT	Project ACCORD tracks the process of clinical guideline development and monitors the implementation of guidelines into clinical practice in order to develop an effective implementation model for conditions prevalent among children with special health care needs enrolled in managed health care delivery systems. This report outlines the results of interviews conducted with representatives from HealthPartners provider groups who were actively involved in implementation of the ICSI Pediatric Asthma Clinical Guideline in 1996. The interviews illustrate the complex nature of guideline implementation within large managed care systems and highlight various models which appear to further the implementation process.

TITLE	**Assuring the Health of Adolescents in Managed Care: A Quality Checklist of Planning and Evaluating Components of Adolescent Health Care**
YEAR	1998
SUPPLIER	National Adolescent Health Information Center (NAHIC)
ADDRESS	UCSF Division of Adolescent Medicine, 1388 Sutter St., Ste. 605A; San Francisco, CA 94109
PHONE	415/502-4856 or Fax: 415/502-4858
PRODUCER	NAHIC
ABSTRACT	This checklist can be used to evaluate and/or plan health care services for adolescents in managed care settings. It is organized into six key components of adolescent health care: adolescent-appropriate quality services, coordination of services, adolescent-sensitive authorization and review process, coordination with public health functions, and adolescent participation in the system of care. The publication also provides for "next steps-ways" results can be used.

TITLE	**Brave New Partnerships: Children with Disabilities, Families and Managed Care**
YEAR	1996
SUPPLIER	The Institute for Health & Disability,
ADDRESS	University of Minnesota, Box 721 420 Delaware St. SE; Minneapolis, MN 55455
PHONE	612/626-3939
PRODUCER	Center for Children with Chronic Illness and Disability, University of Minnesota
ABSTRACT	This monograph reports the results of a survey of the needs and costs for the pediatric population with chronic illness and disability in HealthPartners, a large Minnesota managed care organization. Interviews with families and physicians and financial analysis of the care provided revealed data about services, costs, and family satisfaction. Data also revealed gaps in service and information about effective case management. This publication is available on the IHD web site: <http://www.peds/umn.edu/Centers/idh>. It is also available from EDRS, ED #407 820. For information, call 1-800-443-3742

TITLE	**Child Health Systems Primary Care Assessments Manual: Instruments and Administrative Guidance**
YEAR	1997
SUPPLIER	Lori A. Friedenberg, Women's and Children's Health Policy Center Johns Hopkins School of Public Health,
ADDRESS	624 N. Broadway; Baltimore, MD 21205
PHONE	410/955-2303 or 410/955-3754
PRODUCER	Friedenberg, LA; Cassady CE; Women's and Children's Health Policy Center
ABSTRACT	This comprehensive manual has been developed to provide guidance for use of the Child Health Systems Primary Care Assessment instruments by state and local MCH programs, Medicaid offices, health plans and others. In addition to the instruments, the manual contains information on the definition of primary care used, a typical IRB application process, guidance for locating potential respondents for the consumer/client survey, guidance on training interviewers, and administering the provider and facility surveys. Coding manuals, analysis plans and the analysis program are included.

TITLE	**Children with Special Health Care Needs in Managed Care Organizations: Definitions and Identification, Family Participation, Capitation and Risk Adjustment, and Quality of Care**
YEAR	1996
SUPPLIER	Fox Health Policy Consultants, Inc.
ADDRESS	750 17th St. NW, Ste. 1025; Washington, DC 20006-4607
PHONE	202/223-1500
PRODUCER	Division of Services for Children with Special Needs of the Maternal and Child Health Bureau
ABSTRACT	This 39-page report is a summary of expert work group meetings on four topics related to managed care: identification of children with special needs, family participation, capitation and risk adjustment, and quality of care. For each topic, the discussion includes a problem statement, examples of current research and innovative approaches, and recommended activities. Also included is a list of references. Purchase: $20.

TITLE	**Choosing and Getting the Most From Your Managed Care Plan; Understanding Health Insurance; Insurance Terminology for Families**
YEAR	1997
SUPPLIER	Division of Specialized Care for Children, The University of Illinois at Chicago
ADDRESS	2815 W. Washington, Ste.300, Box 19481; Springfield, IL 62794-9481
PHONE	217/793-2340
PRODUCER	DSCC
ABSTRACT	These pamphlets are designed to help families understand health insurance and managed care issues.

TITLE	**Chronic Care in America: A 21st Century Challenge**
YEAR	1996
SUPPLIER	RWJF Publications
ADDRESS	c/o Best Assembly and Fulfillment Services 20 Meridian Rd.; Eatontown, NJ 07724
PHONE	217/793-2340
PRODUCER	The Institute for Health and Aging, University of California, San Francisco for the Robert Wood Johnson Foundation
ABSTRACT	This publication provides an overview of issues related to the provision of health care and related services for people with chronic health conditions. Sections address: an overview of chronic care, including demographics and analysis of economic costs; the chronic care system, including sources of care and financing issues; stresses in the system, including discussion of unmet needs and caregiving. The last section projects challenges for the 21st century. The appendix profiles programs that serve persons with chronic illnesses. To order by e-mail: Best-Assembly@worldnet.att.net or an electronic verson is available at: <http://www.rwjf.org>.

TITLE	**A Compendium of Federally Funded Projects on Managed Care and Children with Special Health Care Needs**
YEAR	1998
SUPPLIER	Maternal and Child Health Policy Research Center McManus Health Policy, Inc.
ADDRESS	2 Wisconsin Circle, Ste. 700; Chevy Chase, MD 20815
PHONE	202/686-4797
PRODUCER	Maternal and Child Health Policy Research Center
ABSTRACT	This compendium includes a summary of over 50 managed care projects for children with special health care needs (CSHCN) funded by nine federal agencies. The first section summarizes background issues of importance to CSHCN. The second section briefly describes each project

TITLE	**Defining "Medically Necessary" Services to Protect Plan Members**
YEAR	1997
SUPPLIER	Publications Desk, Bazelon Center for Mental Health Law
ADDRESS1	1101 15th St. NW
ADDRESS2	Washington, DC 20005
PHONE	202/467-5730; E-mail: pubs@bazelon.org
PRODUCER	Bazelon Center
ABSTRACT	This 21-page paper is an analysis of what constitutes "medically necessary services." Definitions of "medically necessary" often become the criteria for making decisions about the services a health plan will cover. The paper suggests that states develop criteria requiring that services be designed to achieve appropriate goals and be delivered according to specific principles. The text and footnotes can be printed from the Bazrlon Centers web page (www.bazelon.org).

TITLE	**Evaluating Managed Care Plans for Children with Special Health Needs: A Purchaser's Tool**
YEAR	1998
SUPPLIER	John Reiss, Ph.D.
ADDRESS	Institute for Child Health Policy 5700 SW 34th St., Ste. 323; Gainesville, FL 32608
PHONE	e-mail: jgr@ichp.edu
PRODUCER	CSHCN Continuing Education Institute at Children's Hospital, Columbus, OH; Department of Pediatrics, Ohio State University; Columbus Children's Hospital; Margaret McManus
ABSTRACT	This tool is designed to assist purchasers in selecting and evaluating the capacity of health plans to serve children with or without chronic medical conditions. Section 1 covers pediatric services and cost-sharing requirements that can guide decisions about plan affordability and comparative value of each plan option. Section 2 addresses pediatric provider network capacity and lists questions to informa buyers about assessing the comprehensiveness and organization of each plan's pediatric service delivery system. Section 3 addresses quality assurance and includes a series of questions to better understand the authorization and evaluation of pediatric services within each plan.

TITLE	**Issues Brief: Managed Care: Considerations for Serving Children with Special Health Needs**
SUPPLIER	Minnesota Children with Special Health Needs
ADDRESS	Minnesota Department of Health, 717 SE Delaware St. SE; Minneapolis, MN 55440-9441
PHONE	612/623-5150 or 800-728-5420
PRODUCER	MCSHN
ABSTRACT	This publication outlines pertinent issues regarding the delivery of health care services to children with special health needs (CSHN) by managed care organizations. In addition to general information about CSHN and manage care, the publication addresses decisions about service coverage, access to necessary services, and information about care coordination and compensation.

TITLE	**Managed Care Maze: What About The Children? Video, Parents Guide, Physicians Guide**
YEAR	1997
SUPPLIER	Parent Educational Advocacy Training Center (PEATC)
ADDRESS	10340 Democracy Lane, Ste. 206; Fairfax, VA 22030
PHONE	703/691-7826
PRODUCER	Shirley Robson, SVR Inc. Television Productions
ABSTRACT	This multi-media package contains information for families and physicians about managed care and children with special health care needs (CSHCN). The video illustrates culturally diverse families and their physicians working together to provide the best possible care for CSHCN within various managed care systems. The Parents Guide provides basic information about health care options within managed care and offers suggestions to facilitate partnership and cooperation between parents and health care providers. This publication includes problem-solving strategies and forms parents can copy and use to help organize health care information. The Physicians Guide discusses changing roles for physicians and also addresses family-centered care and cross-cultural competence. Both publications include a resource section. Packages contain a video and either a Parents or Physicians Guide. Additional guides can be purchased. Purchase: $30 (Parents); $50 (Professionals)

TITLE	**Meeting the Needs of People with Chronic and Disabling Conditions in Medicaid Managed Care**
YEAR	1998
SUPPLIER	Families USA.
ADDRESS	1334 G St. NW; Washington, DC 20005
PHONE	202/628-3030
PRODUCER	Families USA
ABSTRACT	This fact sheet outlines important issues that must be considered if Medicaid beneficiaries with chronic or disabling conditions are to receive their health care from managed care plans.

TITLE	**Open the Window on Managed Care; Open the Door to People with Disabilities; Opening the Window on Managed Care: A Workbook for People with Disabilities and Advocates; Opening the Door to People with Disabilities: A Guide for Managed Care Providers**
YEAR	1996
SUPPLIER	Partners in Health, c/o The Coordinating Center
ADDRESS	Brightview Business Center 8258 Veterans Highway, Ste. 13; Millersville, MD 21108
PHONE	410/987-1048
PRODUCER	Partners in Health
ABSTRACT	These publications include information for consumers of managed care services and managed care providers. The pamphlets and workbooks are designed to educate consumers about managed care and providers about people with disabilities so that both can become effective partners in maximizing the benefits of health care. Purchase: $15 plus shipping.

TITLE	**Quality, Quality Assessment, and Quality Assurance Considerations for Maternal and Child Health Populations and Practitioners**
YEAR	1995
SUPPLIER	Child and Adolescent Health Policy Center The Johns Hopkins University, School of Hygiene and Public Health
ADDRESS	624 N. Broadway; Baltimore, MD 21205
PHONE	410/550-5443
PRODUCER	Grason H; Guyer B.
ABSTRACT	This report synthesizes issues related to quality concepts, practices and problems as they apply to maternal and child health. Definitions, domains, and levels of assessment are outlined and discussed. This report also provides information on how these concepts are implemented, and examples of how they are used by MCH professionals to assure quality health care.

TITLE	**Quality Community Managed Care: A Guide for Quality Assurance Measures for Children with Special Health Care Needs**
YEAR	1997
SUPPLIER	Colleen Monahan, DC, MPH; University of Illinois at Chicago; Division of Specialized Care for Children
ADDRESS	1919 W. Taylor St., Room 800, CM/C 618; Chicago, IL 60612-3772
PHONE	312/996-6380
PRODUCER	Monahan C; Harders-Shanahan R; Maloney MM; Song J
ABSTRACT	This guide provides a set of measures that can be used to monitor children with special health care needs (CSHCN) in managed care plans or to monitor services funded by state CSHCN programs. An Adobe PDF verson can be viewed or downloaded from the following URL: <http://www.uic.edu/hsc/dscc/qcmc/qcmchome.htm>.

TITLE	**Speaking Up For Your Child: Advocating in the Health Care System for Your Child with Special Needs**
YEAR	1997
SUPPLIER	Pathfinder Resources, Inc.
ADDRESS	2324 University Ave. W., Ste. 105; St. Paul, MN 55114
PHONE	651/647-6905
PRODUCER	Pathfinder Resources, Inc.
ABSTRACT	This booklet for families of children with special needs is designed to help families develop skills that go beyond what most parents need when caring for their children. Ideally, parents and professionals will work as equal partners to provide the best care possible for their child. The booklet also provides factual information to assist in being an equal partner in the health care team. Volume discounts are available. Purchase: $4.95 (1-10 copies) plus shipping.

TITLE	**Strategies to Enhance Preventive and Primary Care for High Risk Children Served in HMOs**
YEAR	1995
SUPPLIER	McManus Health Policy, Inc.
ADDRESS	2 Wisconsin Circle, Ste. 700; Washington, DC 20815
PHONE	202/686-4797; Fax: 202/686-4791
PRODUCER	McManus, MA; Fox, HB
ABSTRACT	This report suggests practical approaches to assist HMOs in designing improved preventive and primary care services for high-risk children and their families. The first section explains the environmental, behavioral, and biological risk factors affecting today's children and examines the role HMOs could play in the early detection and treatment of health problems associated with these risk factors. The second section of the report presents 15 specific design elements offering HMOs a comprehensive strategy to improve their capacity to deliver such services. The 15 design features were the result of literature reviews, surveys of managed care plans, and reviews of state Medicaid contracts.

TITLE	**Summary Report on the Family Voices Managed Care Survey**
YEAR	1997
SUPPLIER	Nora Wells, Family Voices
ADDRESS	Federation for Children with Special Needs 95 Berkeley St., Ste. 104; Boston, MA 02116
PHONE	617/862-2680
PRODUCER	Family Voices
ABSTRACT	Report of a study of the experiences of families of children with special needs in mananged care and non-managed care. Families in Atlanta, Denver, Des Moines and Seattle were surveyed.

Mental Health

TITLE	**A Family Advocate's Guide: Managing Behavioral Health Care for Children and Youth**
YEAR	1996
SUPPLIER	Publications Desk, Bazelon Center for Mental Health Law
ADDRESS	1101 15th St. NW, Ste. 1212; Washington, DC 20005
PHONE	202/467-5760 or Fax: 202/223-0409
PRODUCER	Bazelon Center for Mental Health Law and Federation of Families for Children's Mental Health
ABSTRACT	This 34-page booklet offers information about how managed care should work for children with mental, emotional or behavioral disorders and recommends strategies for assuring that state systems adhere to these principles. The publication includes a glossary of terms and handouts that can be copied and used to inform state policymakers and managed care entities about family issues. Also available in Spanish. A copy of the pamphlet "Your Family and Managed Care" is included with this publication. Purchase: $9.95 plus postage.

TITLE	**Managed Mental Health Care: What to Look For, What to Ask**
YEAR	1996
SUPPLIER	Substance Abuse and Mental Health Services Administration (SAMHSA), Knowledge Exchange Network (KEN)
ADDRESS	PO Box 4290; Washington, DC 20015
PHONE	800/789-2647
PRODUCER	SAMHSA
ABSTRACT	This pamphlet contains information for consumers about managed care and mental health services. Issues addressed include: provision and exclusion of services, benefits and drawbacks of managed care, the role of physicians and the case manager, membership services, consumer rights and grievance procedures, and Medicaid managed care. To order a copy electronically: <http://www.mentalhealth.org>. DHHS Publication No. (SMA) 96-3097.

TITLE	**SSI–Help for Children with Disabilities**
SUPPLIER	Bazelon Center for Mental Health Law
ADDRESS	1101 15th St. NW, Ste. 1212; Washington, DC 20005
PHONE	202/467-5760 or Fax: 202/223-0409
PRODUCER	Bazelon Center for Mental Health Law
ABSTRACT	This 20 page handbook is for families and advocates on the federal Supplemental Security Income (SSI) program for children with severe mental and physical disabilities. It explains how children can qualify for the benefits and Medicaid coverage. The booklet explains how a family can appeal a denial of benefits and clarifies income and financial restrictions. This booklet interprets the new eligibility rules enacted by Congress in the 1996 welfare-reform law which requires a new more restrictive definition of childhood disability and re-evaluation of many children. Purchase: $3.00 plus shipping.

TITLE	**Your Family and Managed Care**
YEAR	1996
SUPPLIER	Publications Desk, Bazelon Center for Mental Health Law
ADDRESS	1101 15th St. NW, Ste. 1212; Washington, DC 20005
PHONE	202/467-5760 or Fax: 202/223-0409
PRODUCER	Bazelon Center for Mental Health Law and Federation for Children's Mental Health
ABSTRACT	This 16-page pamphlet provides information for families of children with mental, emotional or behavioral disorders about chosing a managed behavioral health care plan and working with the plan in which they are enrolled. The text explains how a well-managed plan can improve their child's access to services, lists pitfalls they should watch for, and offers a checklist to evaluate whether a plan is family-friendly. Also published in Spanish. Volume discounts are available. E-mail: pubs@bazelon.org. Web site:http://www.bazelon.org.

Medicaid and Managed Care

TITLE	**Medicaid Managed Care: An Advocate's Guide for Protecting Children**
YEAR	1996
SUPPLIER	National Association for Child Advocates
ADDRESS	1522 K St. NW, Ste. 600; Washington, DC 20005
PHONE	202/289-0777
PRODUCER	National Association of Child Advocates and National Health Law Program
ABSTRACT	This manual provides a comprehensive examination of the issues surrounding managed care and its impact on children, as well as the strategies being used by advocates across the country to influence the design and implementation of Medicaid managed care programs in their states and localities. Section I presents programmatic and technical information about Medicaid and managed care including chapters on managed care enrollment, plan services, financing and quality. Part II discusses ways advocates can influence the development and implementation of Medicaid managed care programs. Purchase: $40 (non-profit organizations and government agencies; $100 (non-profit organizations).

TITLE	**Medicaid Survival Kit**
YEAR	1996
SUPPLIER	National Conference of State Legislatures, Book Department
ADDRESS	1560 Broadway, Ste. 700; Denver, CO 80202
PHONE	303/830-2054
PRODUCER	National Conference of State Legislatures; King M; Christian SM
ABSTRACT	This publication explains the Medicaid program, proposed changes, and the issues that legislators face when reforming the system. Notebook sections include Medicaid overview, federal changes, major Medicaid populations, public providers, cost containment strategies, including managed care and private sector plans that will insure more people. The loose-leaf format allows for periodic updates. Purchase: $75.

TITLE	**Negotiating the New Health System: A Nationwide Study of Medicaid Managed Care Contracts**
YEAR	1998
SUPPLIER	Center for Health Policy Research, George Washington University
ADDRESS	Attn: Contract Study, 2021 K St. NW, Ste. 800; Washington, DC 20006
PHONE	202/296-6922
PRODUCER	Center for Health Policy Research, George Washington University
ABSTRACT	This publication reviews 54 contracts and RFPs that states were using as of the beginning of 1997. The contracts cover comprehensive managed care service arrangements involving both inpatient and outpatient care, behavioral health, and general health care. Much of this information will be especially helpful to states implementing the State Child Health Insurance Program (CHIP). An executive summary is available. Purchase: $30 (Vol I); $200 (Vol II).

TITLE	**The Effect of Managed Care on Medicaid Financing for Public Programs Serving Children with Special Needs**
YEAR	1996
SUPPLIER	Fox Health Policy Consultants, Inc
ADDRESS	750 17th St. NW, Ste 1025; Washington, DC 20006-4607
PHONE	202/223-1500
PRODUCER	Fox HB; McManus MA; Almeida R; Lesser C.
ABSTRACT	This briefing report, prepared for the National Health Policy Forum, assesses the effects that Medicaid managed care has had on five major public programs serving children with special health care needs (CSHCN): the Title V Program for Children with Special Health Care Needs, the Special Education Program, the Early Intervention Program, the Children's Mental Health Services Program, and Title IV-B Child Welfare services for children in foster care. The report provides an overview of the five programs, reviews the extent of Medicaid financing for these programs prior to managed care, and examines Medicaid financing policies for the program services and eligible populations under managed care. Purchase: $20.

Family Voices

Family Voices is a national grassroots organization that provides information and education concerning policy of children with special health needs (CSHN). They have produced a number of publications about managed care and CSHN. For additional information:

Family Voices
PO Box 769, Algodones, NM 87001
867/2368 or 888/835-5669 (Toll-free)
E-mail: kidshealth@familyvoices.org
Web site: http://familyvoices.org

TITLE	**Alphabet Soup: Health Care Definitions for Children with Special Health Care Needs**
ABSTRACT	This sheet defines health care terminology, especially terms that are relevant to managed care.
TITLE	**Children with Special Health Care Needs in Managed Care: Questions to Ask and Answer**
ABSTRACT	This information sheet provides a framework of questions to use when examing the conduct and services offered by managed care organizations to children with special health needs (CSHN). The questions can guide consumers and families in chosing a health care plan for their family or can help families in advocating for services that support CSHN in managed care plans.
TITLE	**Introduction to Managed Care for Children with Special Health Care Needs**
ABSTRACT	This brochue provides families of children with special health care needs an introduction to managed care. In addition to providing basic information about managed care, the brochure: 1) Lists important questions to ask; 2) Defines managed care terms; and 3) Provides a place for parents to record important names and phone numbers.
TITLE	**Managed Care for Children with Special Health Care Needs: By Families for Families**
ABSTRACT	This one page sheet contains information included in the family Voices "Managed Care for Children with Special Health Care Needs" brochure. It explains important features families should know about managed care.
TITLE	**Resources for Learning About Health Care Reform**
ABSTRACT	This bibliography lists documents useful for understanding and analyzing health care reform plans and also lists organizations that have prepared papers about health care reform.

Medical Home for Children with Special Health Needs

The following publications were produced by the American Academy of Pediatrics and the AAAP's Medical Home Program for Children with Special Needs, a program that provides educational materials, technical assistance, training programs and advocacy to primary and subspecialty pediatricians who care for children with special needs. For additional information contact:

American Academy of Pediatrics
PO Box 927; Elk Grove Village, IL 60009-0927
800/433-9016
Web site: www.aap.org

TITLE | **A Pediatrician's Guide to Managed Care** (1995)

ABSTRACT | A comprehensive resource guide for physicians managed care enviroments. It provides "how-to" information: evaluating capitation rates and understanding carve-outs/exclusions; negotiating managed care contracts; assessing managed care organizations and identifying the legal and antitrust issues related to negotiations and organizations. A glossary of terms, AAP policy statements, CPT and ICD-9-CM codes for pediatric services, and valuable practice and contract checklists are also included.

TITLE | **How to Use Your Managed Care Plan Effectively: Questions and Answers for Families with Children**

ABSTRACT | This brochure provides instruction for families enrolled in managed care plans. The following topics are addressed: accessing pediatric primary and specialty providers, understanding authorization for care, linking with other child and family services in the community, cost-sharing requirements, accessing out-of-plan or out-of-area services, and plan exclusions/limitations.

TITLE | **Managed Care and Children with Special Health Care Needs: Creating a Medical Home**

ABSTRACT | An explanation of the role of the pediatrician in the managed care environment and ways to balance service utilization management needs and the provision of quality health care for children with special health care needs. Principles that allow effective co-management between primary care physicians and pediatric specialists are listed. The role of the specialist in managed care also is addressed. Contact the AAP for information about other resource materials addressing the needs of families and physicians in a managed care environment.

TITLE | **Purchasing Quality Pediatric Care in Commercial Managed Care Plans**

ABSTRACT | This brochure was designed to educate health care purchasers including corporate benefits officers, health care benefit consultants, and state legislators on the need to include comprehensive quality pediatric health care services in all managed health care plans.

TITLE | **Strategies for Managed Care: Slide Presentation** (1996)

ABSTRACT | This slide presentation focuses on managed care models, reimbursement options, and negotiating a managed care contract. Presentations can be used in education of health care professionals, local health coalitions, resident groups, hospital medical staff meetings, or other forums to address the issues of pediatricians and managed care. It is best when used in conjunction with the manual "A Pediatrician's Guide to Managed Care." (See UI # 14681)

TITLE | **The Medical Home and Early Intervention: Linking Services for Children with Special Needs** (1995)

ABSTRACT | A resource for pediatric health care providers promote a continuum of care for young children with special health care needs. Two major components of the continuum are discussed: the provision of community-based health services through the concept of the medical home and the role of early intervention programs for infants and toddlers with disabilities in providing the statewide system of information for early intervention services.

TITLE | **The Medical Home Checklist** (1998)

ABSTRACT | This checklist itemizes services and benefit policy needed to ensure that children with special needs have a medical home. It defines the ideal characteristics of a medical home and becomes something to strive for if programs are not providing all of the listed services.

TITLE | **The Medical Home Contact Network** (1998)

ABSTRACT | This publication lists state pediatric health care professionals who have identified themselves as having expertise in caring for children with special health needs (CSHN) and who are willing to serve as a resource to others. Members of the network receive eductional and presentation materials that can be used to advocate for policies and services that benefit CSHN.

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